



# Health Technical Services Project



## Discussion Papers on HIV/AIDS Care and Support

### Integrating HIV/AIDS Prevention, Care, and Support: A Rationale

Prepared by  
Messaye Girma  
Helen Schietinger

Discussion Paper Number 1

June 1998

UNITED STATES AGENCY FOR INTERNATIONAL DEVELOPMENT

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This report is part of a series of papers on HIV/AIDS care and support.  
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### About HTS

The Health Technical Services Project provides short- and medium-term technical assistance to USAID — specifically, to regional bureaus, regional and country missions, and the Office of Health and Nutrition in the Center for Population, Health and Nutrition of the Bureau for Global Programs, Field Support, and Research (G/PHN/HN). This technical assistance supports USAID programs in maternal and child health, nutrition, health policy reform, HIV/AIDS, and environmental health. HTS activities are concentrated in three broad technical areas: project design, policy and strategy, and evaluation and monitoring.

HTS's work is grounded in the four complementary values that guide USAID's efforts to reengineer its operations:

- # a customer focus
- # participation and teamwork
- # empowerment and accountability
- # management for results.

## Foreword

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**T**he U.S. Agency for International Development seeks to develop and promote effective strategies for providing basic care and support to those affected by HIV/AIDS. This series of Discussion Papers on HIV/AIDS Care and Support represents a first step in this effort.

HIV/AIDS care and support mitigate the effects of the pandemic on individuals, families, communities, and nations. Such interventions are an important component of the overall response to HIV/AIDS because they increase the impact of prevention strategies and mitigate the negative consequences of the epidemic on the prospects for sustainable development.

This series of Discussion Papers covers several key issues related to care and support:

- # Human rights and HIV/AIDS
- # Palliative care for HIV/AIDS in less developed countries
- # Preventing opportunistic infections in people infected with HIV
- # Psychosocial support for people living with HIV/AIDS
- # Community-based economic support for households affected by HIV/AIDS
- # Responding to the needs of children orphaned by HIV/AIDS
- # Systems for delivering HIV/AIDS care and support.

Each paper provides a preliminary review of some of the current thinking and research on these broad and complex topics. It is important to note that the papers are not meant to be comprehensive — time and resource constraints prevented the authors from reviewing all the relevant literature and from contacting all the people who have valuable experience in these and related fields. Nor have they been subject to technical or peer review. Their purpose is to stimulate a broad conversation on HIV/AIDS care and support that can help USAID define its future program activities in this area. We welcome your participation in this process.

## Discussion Papers on HIV/AIDS Care and Support

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Two additional papers on the topic of voluntary counseling and testing were prepared with USAID support:

# The Cost Effectiveness of HIV Counseling and Testing

# Voluntary HIV Counseling and Testing Efficacy Study: Final Report.

These two papers are available from the IMPACT Project, Family Health International, 2101 Wilson Boulevard, Suite 700, Arlington, VA 22201; [www.fhi.org](http://www.fhi.org).

Please direct your requests for copies of papers in the Discussion Series on HIV/AIDS Care and Support and your comments and suggestions on the issues they address to the Health Technical Services (HTS) Project, 1601 North Kent Street, Suite 1104, Arlington, VA 22209–2105; telephone (703) 516-9166; fax (703) 516-9188. Note that the papers can also be downloaded from the Internet at the HTS Project's web site ([www.htsproject.com](http://www.htsproject.com)).

—Linda Sanei, Technical and Program Advisor,  
Health Technical Services Project

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# Integrating HIV/AIDS Prevention, Care, and Support: A Rationale

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HIV/AIDS “care and support” is defined as an intervention or set of interventions whose purpose is to mitigate the impact of the HIV/AIDS epidemic on individuals, families, communities, and nations. Care and support activities therefore are broad in nature and are critical to the continued efforts of communities, governments, and donors to promote sustainable development in the face of the HIV/AIDS epidemic. The benefits of care and support interventions are threefold: First, care and support mitigate the effects of the HIV/AIDS pandemic on individuals, families, communities, and nations, thereby promoting their prospects for sustainable development. Second, care and support interventions help prevent further HIV/AIDS transmission by enhancing the effectiveness of prevention efforts. Third, care and support are rights because they promote access to basic health and welfare consistent with the Universal Declaration of Human Rights, and they are therefore ends in themselves. Discussions about integrating HIV/AIDS prevention, care, and support should acknowledge the fact that care and support enhance prevention, while prevention enhances care and support — a two-way effect that sustains a cycle of benefits.

For almost 15 years, HIV/AIDS programs in developing countries have focused almost exclusively on preventing the spread of HIV. Given the high cost of treatment and the lack of a cure, many national governments, donors, and nongovernmental organizations (NGOs) have invested their resources in prevention rather than in providing care and support to those who are already



infected, or in assisting families, communities, and nations that have been buffeted by the pandemic.

Yet the separation between “prevention,” “care,” and “support” is becoming increasingly artificial for many health care providers, outreach workers, peer counselors, volunteers, and others who work at the community level. Indeed, many believe that the absence of programs to provide care and support for those affected by HIV/AIDS may actually weaken and undermine prevention efforts. This is particularly true in countries with generalized epidemics<sup>1</sup> where HIV has spread far beyond the original subpopulations with high-risk behavior, so that HIV prevalence among women attending urban antenatal clinics is 5 percent or more. Those who support an emphasis on prevention fear that attempting to meet the burgeoning need for HIV/AIDS care and support would drain precious dollars from prevention efforts, making it all but impossible to slow the spread of the pandemic. There is growing evidence, however, that providing care and support to those affected by HIV/AIDS actually strengthens prevention efforts, and that focusing single-mindedly on prevention actually undermines the credibility of HIV/AIDS programs among the very people they are intended to assist, especially in countries with high HIV prevalence rates.

### **CURRENT KNOWLEDGE ON HIV/AIDS CARE AND SUPPORT: AN OVERVIEW OF THE DISCUSSION PAPERS IN THIS SERIES**

The seven Discussion Papers on HIV/AIDS Care and Support published as part of this series explore the rationales for devoting resources to care and support and for integrating such activities into programs that also promote prevention. Six of the papers first explore current knowledge on the role of particular types of care and support interventions in mitigating the effects of the pandemic, enhancing prevention efforts, and promoting people’s basic rights to health and welfare, and, second, discuss methods for providing care and support services to the target beneficiaries. A seventh paper specifically explores some lessons learned about appropriate systems for delivering care and support to people and communities affected by HIV/AIDS.

# *Human Rights and HIV/AIDS*: HIV/AIDS prevention and care programs engage the full range of human rights — those freedoms and entitlements

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<sup>1</sup>For a description of the distinctions between “nascent,” “concentrated,” and “generalized” stages of HIV/AIDS epidemics, see Figure 4 on page 21.

invested in each person at birth which are universal and inalienable. To prevent the further spread of HIV while protecting the human rights of those who are infected with HIV and those who are not, HIV/AIDS policymakers must review the legality of HIV/AIDS policies; evaluate their public health goals; assess whether the policies can achieve those goals; and weigh whether the benefits outweigh the financial and human rights burdens. (Lazzarini 1998)

- # *Palliative Care for HIV/AIDS in Less Developed Countries*: Palliative care for HIV/AIDS encompasses a broad set of interventions, from initial diagnosis to the final stages of the disease, in response to the physical, emotional, psychosocial, spiritual, and bereavement needs of people living with HIV/AIDS and their families and caregivers. Palliative care is comprehensive care which is affordable and can be delivered in the home, when there is a well-functioning referral system and supportive family structure. (Sanei 1998)
- # *Preventing Opportunistic Infections in People Infected with HIV*: As immunodeficiency progresses, people with HIV and AIDS become susceptible to a wide variety of opportunistic infections (OIs). The spectrum of OIs varies among regions of the world. Tuberculosis is the most common serious OI in Sub-Saharan Africa and is also more common in Latin America and in Asia than in the United States. Bacterial and parasitic infections are common in Africa; protozoal infections are also common in Latin America; and fungal infections appear to be common in Southeast Asia. Despite limited health resources in these regions, some measures that are recommended to prevent OIs in the United States may be useful for prolonging and improving the quality of life of HIV-infected people. Research is needed to determine the spectrum of OIs and the efficacy of various prevention measures in less developed nations, and health officials need to determine a minimum standard of care for HIV-infected people. (Kaplan et al. 1996/1998)
- # *Psychosocial Support for People Living with HIV/AIDS*: Psychosocial support includes a range of interventions to enable people to function in the face of the sometimes overwhelmingly adverse circumstances and problems caused by HIV and AIDS. These include accepting a positive HIV test, living positively with HIV, facing discrimination and stigma, coping with loss and grief, nurturing affected children, and, for health workers and counselors, combating burnout. Psychosocial care can be provided by professionals and nonprofessionals, including family, friends, neighbors, and others in the community. Therefore, it offers an opportunity for communities to interact constructively with people affected by HIV/AIDS and represents a sustainable,

community-based activity that requires few if any outside resources.  
(Schietinger 1998)

- # *Community-Based Economic Support for Households Affected by HIV/AIDS:* Because the burden of HIV/AIDS is felt first by individuals and their families, the first line of response should be to mitigate the impact on those households, in particular, by improving their earning capacities. When families are no longer able to cope, they turn to members of their community, and projects that strengthen communities' coping mechanisms will become increasingly significant as an epidemic continues. Planners should therefore consider a two-pronged approach to mitigating the socioeconomic consequences of HIV/AIDS on affected communities: building the economic resources of households, primarily through microcredit programs, and supporting the creation of, and ensuring access to, community safety nets. (Donahue 1998)
- # *Responding to the Needs of Children Orphaned by HIV/AIDS:* The growing number of orphans in countries hard-hit by HIV/AIDS suffer a variety of deprivations and vulnerabilities. These include the loss of their families, depression, increased malnutrition, lack of immunizations or health care, increased demands for labor, lack of schooling, loss of inheritance, forced migration, homelessness, vagrancy, starvation, crime, and increased exposure to HIV infection. Given the scale of the problems, the first line of response from the affected children, families, and communities will be insufficient. Recent experience suggests that five basic interventions strategies can help maximize the impact of local, community-based responses: strengthening the capacity of families to cope with their problems; stimulating and strengthening community-based responses; ensuring that governments protect the most vulnerable children; building the capacities of children to support themselves; and creating an enabling environment for the development of appropriate responses. (Hunter and Williamson 1998)
- # *Systems for Delivering Care:* Most programs in developing countries that provide care to people affected by HIV/AIDS have been initiated at the local level in response to local needs, but these community-based programs are being overwhelmed. Meeting the growing demand will require integrating such programs into the systems that deliver other types of health services (i.e., health care facilities and workplaces) and decentralizing them to adequately distribute resources to individual communities. Replicating successful community-based programs on a regional or national level will require technical assistance, expanded local capacity, and new and improved linkages and referral systems between health facilities and among such facilities and

programs implemented outside the formal health sector. Such efforts should seek to ensure that all people have access to care, regardless of where they live or their socioeconomic status. (Schietinger and Saneii 1998)

Three main themes recur in all the seven of the Discussion Papers in this series:

- # Care and support interventions **mitigate the effects of the HIV/AIDS pandemic** on individuals, families, communities, and nations, thereby promoting their prospects for sustainable development.
- # Care and support interventions **help prevent further HIV/AIDS transmission** by enhancing the effectiveness of prevention efforts.
- # Care and support are rights because they **promote access to basic health and welfare** consistent with the Universal Declaration of Human Rights. They are therefore ends in themselves.

## INTRODUCTION TO THIS DISCUSSION PAPER

This paper, *Integrating HIV/AIDS Prevention, Care, and Support: A Rationale*, provides a starting point for discussions about HIV/AIDS care and support by

- # defining “care and support” in the context of HIV/AIDS in developing countries
- # outlining how program interventions that provide care and support to those affected by HIV/AIDS provide three fundamental benefits — mitigation, prevention, and promotion of human rights
- # introducing the related concepts of the “prevention-care dynamic” and the “prevention-and care continuum”<sup>2</sup> that are at the heart of the international debate surrounding the integration of prevention, care, and support
- # reviewing how care and support activities can be integrated with prevention activities
- # reviewing some cross-cutting principles that should be reflected in such integrated programs

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<sup>2</sup>See the discussion of the prevention-care dynamic in Section 2, beginning on page 14, and the discussion of the prevention-and-care continuum in Section 4, beginning on page 21.

- # drawing some general conclusions about the rationale for integrating HIV/AIDS prevention, care, and support activities
- # summarizing recommendations arising from the other discussion papers in series both for implementation and for research of care and support interventions.

### WHAT COMPRISES HIV/AIDS CARE AND SUPPORT?

**HIV/AIDS “care and support” are defined as interventions or sets of interventions whose purpose is to mitigate the impact of the HIV/AIDS epidemic on individuals, families, communities, and nations.**

Care and support activities therefore are broad in nature and are critical to the continued efforts of communities, governments, and donors to promote sustainable development in the face of the HIV/AIDS epidemic.

For the purposes of this paper, care and support are distinguished from each other as follows:

- # “Care” involves services to stabilize and/or improve the mental and physical health of individuals infected and affected by HIV and AIDS.
- # “Support” involves interventions to stabilize and/or improve community and societal systems affected by the epidemic.

## 1. CARE AND SUPPORT MITIGATE THE EFFECTS OF THE HIV/AIDS PANDEMIC

The HIV/AIDS pandemic is one of the most important problems facing developing nations. Already, HIV/AIDS has begun to reverse 30 years of hard-won gains in economic and social development. Consider the effects on a country with a generalized epidemic:

- # Individual health and family welfare decline dramatically.
- # Community welfare and cohesion are threatened.
- # Health systems are strained to their limits.
- # Productive sectors of the economy face increased costs and reduced productivity.
- # Societal and political stability are threatened.

These negative effects, in turn, undermine countries' efforts at sustainable development (see Figure 1). The severity of the HIV/AIDS pandemic's consequences for sustainable development are illustrated in a recent study which compares one measure of economic and social development, the Human Development Index (HDI),<sup>3</sup> with HIV/AIDS data for 60 countries (Godwin 1997). The HDI improved much more slowly in countries with severe epidemics; on average, a 1 percent increase in HIV prevalence caused a loss of human development of 2.2 years, as measured by the HDI. For example, the study showed that in 1992, Zambia's HDI would have been almost 20 percent greater without the epidemic. Overall, the study found that improvements in the HDI were found to be much less in countries with generalized epidemics.

Below is a review of some of the negative effects of the HIV/AIDS pandemic and some illustrations of how care and support interventions can mitigate these negative effects. The examples included are drawn from the other Discussion Papers in this series, which each draw on and synthesize a variety of research, real-world experience, and other evidence showing the mitigation effects of care and support. The reader is referred to these papers for further information.

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<sup>3</sup>The Human Development Index is a tool developed by the United Nations Development Programme (UNDP) to measure development progress based on life expectancy, adult literacy, average educational attainment, and real GDP per capita.

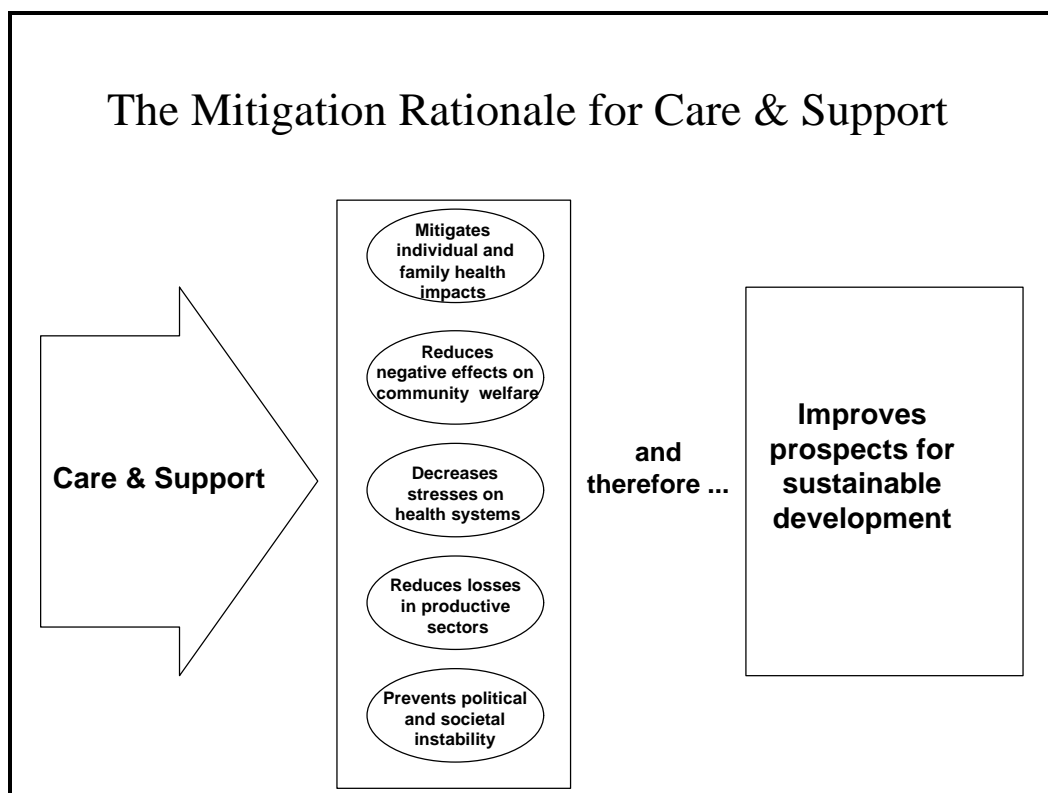


Figure 1. The Mitigation Rationale for Care and Support

### 1.1 The Negative Effects on the Health and Welfare of Individuals and Families

The impact of the epidemic is first felt by the person living with HIV/AIDS (PLWHA), and his or her family or household members. The most obvious impact is on the life expectancy and health of the PLWHA. Over 30 million people have already been infected with HIV, and the daily rate of infection is now close to 16,000 (UNAIDS 1997). As a result, life expectancy at birth has declined significantly in many developing countries (according to the U.S. Bureau of the Census 1996, 1997). Children born to women infected with HIV have a reduced

chance of survival both because of vertical HIV transmission and because of the mothers' diminished capacity to care for them (Hunter and Williamson 1998a). Household income is threatened as the infected become less productive and their families give up work to care for the sick (Armstrong and Bos 1992; Tibaijuka 1997; The Panos Institute 1992). Reduced income, combined with increased medical expenses, in turn threatens affected households' food supply, their ability to pay for education or health care for surviving family members, and their ability to invest in productive inputs for generating future income (Armstrong and Bos 1992). Children orphaned by AIDS become vulnerable to increased malnutrition, lack of health care, increased demands for labor, loss of inheritance, homelessness, vagrancy, and HIV infection (Hunter and Williamson 1998a, 1998b).

**Some Negative Effects of HIV/AIDS on Individuals, Families and Households**

- P Sickness and death
- P Need for care
- P Loss of income
- P Loss of productivity
- P Reductions in nutrition
- P Breakup of families
- P Orphanhood
- P Increased dependency ratios and pressure on surviving adults caring for additional family members
- P Psychological losses and burdens related to sickness, death, decline in well being and increased insecurity
- P Loss of the family's adult members at their most productive ages.

The provision of care and support can mitigate the effects of HIV/AIDS on individuals and can prevent the downward spiral that overwhelms their families and households. Palliative care can prolong life and reduce the physical discomfort associated with HIV infection.<sup>4</sup> Psychosocial care can improve the emotional well-being and coping mechanisms of PLWHAs and their families, enabling them to remain productive. Economic support mechanisms can improve families' capacities to stabilize their income in the face of adult illness and death from AIDS. Protection of human rights can reduce the discrimination and stigma to which people and families affected by HIV/AIDS are often subjected.

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<sup>4</sup>In this series of Discussion Papers, "palliative care" is defined as the range of interventions that improve and the physical health of PLWHAs and the psychosocial and emotional welfare of PLWHAs and their families and caregivers. Therefore, palliative care encompasses clinical care, pain management, nutritional support, and management of opportunistic infections for PLWHAs, as well as emotional, psychological, and bereavement support for families and caregivers. (Sanei 1998)



### 1.2 The Negative Effects on Community Welfare

As the HIV/AIDS epidemic progresses and the number of people dying from HIV-related disease continues to rise, the negative social and economic effects reverberate throughout communities. HIV/AIDS stretches traditional social systems beyond their capacity. For example, communities are called upon to support and participate in mourning rituals. In many communities, contributions to offset burial costs are mandatory; the bereaved family needs help to dig the grave; and everyone provides comfort to the surviving family members during the mourning period.

Traditional mourning periods often forbid planting and other agricultural work for anywhere from one to seven days (Tibaijuka 1997; Barnett 1990; see also Donahue 1998). In areas with high levels of AIDS mortality, the pressures these rituals place on communities can be extreme.

Community members also may have an obligation to share in the care of orphans. In many societies, if there is no extended family to take in orphans, the norm is for the community to step in or to help adolescents who take over the household. A community's capacity to fulfil this obligation, however, is being strained as the numbers of orphans in areas with generalized epidemics increase (Hunter and Williamson 1998a). As the resources of individual households decline, the assistance available from the community safety net also dwindles (Corbett 1988).

Care and support can mitigate the effects of the epidemic on communities. For example, support for establishing and increasing access to community safety nets (such as community insurance schemes) can reduce the economic impact of the devastation of one household on others in the community. The prophylaxis and treatment of opportunistic infections in PLWHAs can protect the community from increased risk of diseases such as tuberculosis. The provision of psychosocial care to people affected by HIV and AIDS can reduce the polarizing effects of stigma and discrimination on the social cohesion of the community.

#### Some Negative Effects of HIV/AIDS on Community Welfare

- P Decline in availability of social services
- P Increased risk of the spread of opportunistic infections
- P Loss of jobs and productive potential
- P Loss of community coherence
- P Polarization as a result of stigma and discrimination
- P Loss of traditions and rituals.

### 1.3 Strains on Health Systems

In countries with generalized HIV/AIDS epidemics, health systems are reeling from the increased demands associated with the growing numbers of people with HIV-related disease. In Tanzania, for example, the treatment costs for HIV/AIDS were already consuming 50 percent of the nation's operational health budget by 1991 (Mann and Tarantola 1992), and this level of impact is also apparent in some countries in Asia (Bloom and Lyons 1993). One consequence is that higher utilization of hospital care by people with HIV-related disease is reducing access to medical care for people with other diseases (World Bank 1997). This rationing effect is compounded by increased mortality among health care professionals as a result of HIV/AIDS (Buve et al., 1994).

#### Some Negative Effects of HIV/AIDS on Health Systems

- P Health resources such as hospital beds, personnel, drugs, and home care are increasingly absorbed in providing care for persons with HIV/AIDS, reducing the amount of resources which can be spent on other health problems
- P The burden of managing the interaction of HIV/AIDS and other diseases, such as tuberculosis, increases
- P Increased costs of reducing infant and child mortality
- P Loss of vital health sector personnel
- P Demoralizing effects of increased mortality and absorption of resources.

AIDS also increases the prevalence of opportunistic infections (such as tuberculosis) that are already widespread in the affected regions (Raviglione et al. 1997; Raviglione et al. 1996; Maher et al. 1997).

Appropriate care and support mechanisms can reduce the burden of the epidemic on health systems. Effective home-based palliative care models, for example, can help families manage the effects of HIV-related disease on PLWHAs at home, reducing the use of more costly HIV-related hospitalizations.<sup>5</sup> This, in turn, enables hospitals to treat more patients with other, non-HIV-related health problems.

### 1.4 The Negative Impact on the Productive Sectors

The productive sectors of a nation's economy — agriculture, manufacturing, services, and foreign trade — are disproportionately affected by the HIV/AIDS pandemic because HIV infection is concentrated among people who are in their

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<sup>5</sup>The World Bank estimates that basic care for an individual infected with HIV can range from \$200 to \$400 per DALY (Disability Adjusted Life Year) gained. Home care is estimated to cost \$30–\$75 per DALY gained. (World Bank 1997)

most productive years (between ages 20 and 40). In countries with generalized epidemics, many firms have experienced rising expenses and declining profits (Forsythe et al. 1996). These result from significant increases in the costs of absenteeism and attrition of staff who become sick, the costs of hiring and training new staff or retraining existing staff to fill gaps, and increased costs of burial compensation and bereavement benefits (USAID 1996).

The negative effects on agricultural production are important. Agriculture is the most important economic sector in many African countries severely affected by HIV/AIDS, and it is estimated that the pandemic will cause a 10–25 percent overall drop in crop yields in Africa (UNDP 1994).

Care and support mechanisms can do a lot to cushion productive sectors of the economy from the negative effects of the HIV/AIDS epidemic. For example, palliative care for PLWHAs, particularly effective treatment of opportunistic infections, can help them continue working longer, reducing rates of worker attrition and lowering the costs of worker replacement. Providing peer support to people who test positive for HIV can offer them hope and motivate them to stay economically productive as long as possible. Community-based economic support mechanisms can protect the capacity of households to sustain high-yield agricultural activities. Protecting the property rights of women widowed by AIDS can allow them to remain economically productive and to keep their children in school, thereby promoting future worker productivity.

### **Some Negative Effects of HIV/AIDS on the Productive Sectors**

- P** Loss of manpower in vital industrial sectors
- P** Loss of manpower in subsistence and commercial agriculture and declining agricultural land base
- P** Loss of personnel in social sectors, including education and social services
- P** Increased labor costs and reduced profitability for private sector firms.

### **1.5 The Negative Impact on Societal and Political Stability**

The HIV/AIDS epidemic contributes to and is exacerbated by social unrest and political instability (US Department of State 1992; Hamilton 1994; CSIS

### **Some Negative Effects of HIV/AIDS on Societal and Political Stability**

- P** Population shifts due to both mortality and migration
- P** Increase in violence associated with crime and stigma
- P** Instability in community leadership as a result of mortality-associated turnover.

1994). As community leaders die of AIDS, for example, they may not be readily replaced by mature individuals. As community safety nets are stretched beyond their limits and more children are orphaned, they may congregate in urban areas and learn to depend on petty theft and commercial sex work for their survival. Increasing rates of destitution, violence, and delinquency are one result of the fear, stigma, and discrimination suffered by those with HIV and AIDS. Finally, national security could be compromised in some countries as HIV infection increases among military recruits.

Care and support interventions can have an important stabilizing effect on societies heavily affected by the epidemic. Anti-discriminatory messages, the provision of palliative care, and support for community safety nets catalyze positive rather than negative community responses to the epidemic. When orphaned children have better assurances of economic and social security, they have fewer incentives to resort to theft and commercial sex work to survive. Likewise, men, women and children who can find adequate economic and social support from within their communities will not be forced to migrate in search of income.

## 2. CARE AND SUPPORT HELP PREVENT HIV/AIDS TRANSMISSION: “THE PREVENTION-CARE DYNAMIC”

A second important rationale for care and support interventions is the increasing evidence of a prevention-care dynamic — a “positive feedback loop” in which care and support enhance the effectiveness of prevention efforts, and prevention enhances the capacity to provide care and support (see Figure 2).<sup>6</sup>

How does this prevention-care dynamic work? Care and support promote the effectiveness of prevention efforts by strengthening the delivery of prevention services and reducing the vulnerability of the beneficiary individuals and communities to HIV. More effective prevention interventions, in turn, reduce the burdens associated with HIV infection and AIDS on families, communities, commercial firms, and the public health system, thereby increasing the resources available for care and increasing the motivation to provide it. Below are four examples of the prevention-care dynamic.

### 2.1 STI Treatment Reduces HIV Transmission

The provision of treatments for sexually transmitted infections (STIs) to PLWHAs reduces the efficiency of HIV transmission. For example, one study found that the quantity of HIV-1 in semen is increased 10 fold in the presence of urethritis (Cohen et al. 1997). *STI treatment — a care intervention — therefore, has an important prevention effect both by reducing the infectivity of PLWHAs and through the attendant counseling that encourages safer sexual behaviors.*

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<sup>6</sup>The existence of a prevention-care dynamic provides the basis for the concept of a prevention-and-care continuum, which asserts that appropriate community, national, and international responses to HIV/AIDS will likely be characterized by the integration of prevention, care, and support interventions at every stage of the epidemic. See Section 4 for a further description of the concept of the prevention-and-care continuum.

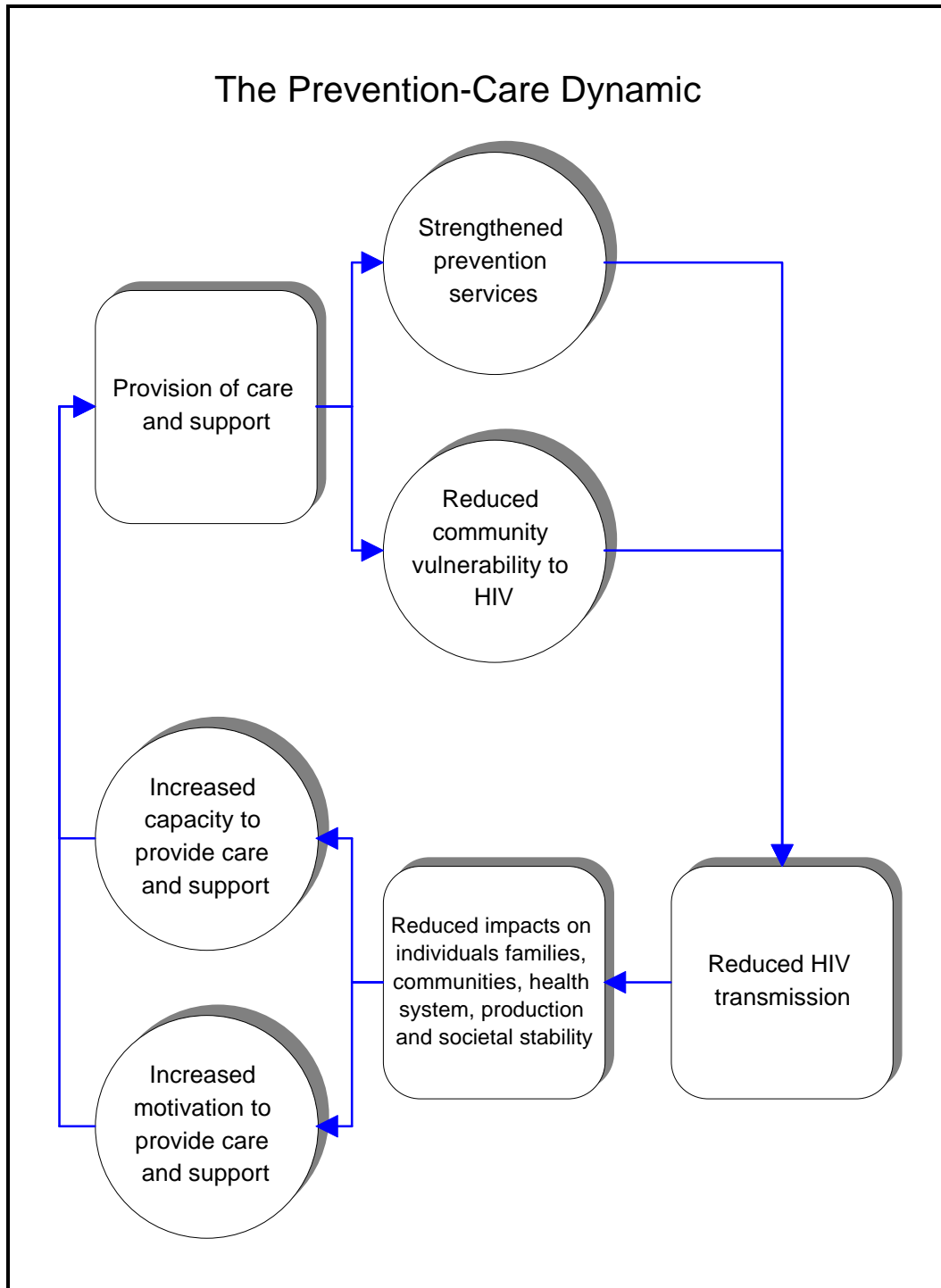


Figure 2. The Prevention–Care Dynamic: A Positive Feedback Loop

## 2.2 Protection of Human Rights Enhances Prevention Efforts

Societies that do not protect and promote key human rights create fertile ground for the spread of HIV. Women and children who are exploited in the sex or drug trades are vulnerable to HIV infection. Girls who are denied equal access to education and women who cannot get jobs or credit are vulnerable to HIV infection. People whose governments stifle the full and free exchange of information or block access to scientific advances are vulnerable to HIV infection. People who lack the means to earn an adequate standard of living, social security, food, or education are vulnerable to HIV infection. Societies that try to reduce the spread of HIV through coercive policies may deceive themselves about the effectiveness of their response to the epidemic, drive those affected underground, or create pockets of vulnerability. (Lazzarini 1998)

Policymakers, advocates, and donors can consider local or national respect for key human rights to be a measure, albeit partial, of societal vulnerability to HIV infection. (Lazzarini 1998) The converse is also true: Effectively promoting and enforcing the rights of communities threatened by the epidemic reduces their vulnerability, thereby enhancing prevention efforts.

People who are vulnerable to HIV/AIDS, many of whom are already marginalized within their communities, will remain fearful of being stigmatized unless they have some assurances that their basic civil rights will be protected, including their right to freedom from discrimination. On the other hand, people at high risk for HIV/AIDS who are assured of civil rights protections are more likely to come forward for voluntary HIV counseling and testing and engage in safer behaviors. Moreover, freedom from the fear of discrimination empowers people living with HIV/AIDS to become visible, active, and effective agents for disseminating HIV prevention information and education. *Effective promotion and enforcement of the human rights of vulnerable populations, therefore, can strengthen the delivery and effectiveness of HIV prevention services.*

## 2.3 Provision of Palliative Care Enhances Prevention Efforts

Palliative care can help prevent HIV transmission in large part by alleviating suffering, providing hope to PLWHAs, and allowing the families of PLWHAs to adjust emotionally, psychologically, and economically to the effects of HIV and AIDS on their households (Sanei 1998). Medical and psychosocial counseling reinforces the determination of PLWHAs to remain economically and socially

productive. Treatment of common ailments associated with HIV/AIDS and pain management alleviates negative HIV/AIDS-related symptoms and increases the independence and well-being of PLWHAs. Nutritional support and management of opportunistic infections increase PLWHAs' stamina and longevity and enhances their quality of life.

These direct benefits of palliative care, in turn, reduce the pressures on their family members to place themselves at risk for infection: women partners and children of PLWHAs face less pressure to resort to commercial sex work for survival; and male partners of PLWHAs face less pressure to migrate away from their communities to escape discrimination. Finally, PLWHAs themselves practice safer sex behaviors with their partners. In these ways, *palliative care can reduce the vulnerability of families and communities to HIV.*

Moreover, the community-based nature of many palliative care services promotes interaction between PLWHAs and members of their community, as volunteers, neighbors, merchants, and local service providers. This direct contact also conveys to the community that HIV/AIDS is indeed a reality and motivates other community members to promote prevention activities within the community. In these ways, *palliative care enhances the role of PLWHAs as prevention partners, enhancing the effectiveness of prevention efforts in the community.*

An evaluation of The AIDS Support Organization (TASO), a community-based support organization in Uganda, revealed that care, defined as medical treatment, counseling, and nursing care, helped people to plan for the future, practice safer sex, and seek early treatment for infections. Counseling also helped clients cope with HIV infection. Of the 730 TASO clients surveyed, 90% had revealed their serostatus, 79% felt their HIV status was accepted by their families, and 76% perceived acceptance in their communities. (MacNeil 1996)



### 2.4 More Effective Prevention Efforts Enhance the Provision of HIV/AIDS Care and Support

Enhanced prevention effectiveness slows the spread of HIV and the incidence of AIDS in a given community. As a consequence, many individuals and their families avoid the economic, psychosocial, emotional, social, and other pressures attendant with HIV/AIDS. Communities face reduced pressures on their leaders, infrastructures, economies, norms, and traditions. Productive sectors face reduced losses associated with absenteeism and rapid employee turnover. Societies and countries face reduced strains on their health systems, reduced losses of foreign exchange, greater potential for growth and development, and greater stability. *These reduced pressures enhance the flexibility and capacity of families, communities, commercial firms, and governments to provide care and support.*

Furthermore, as Figure 7 demonstrates, when care and support strategies both enhance the effectiveness of prevention efforts and mitigate the impact of HIV/AIDS on individuals, families, and communities and on general social and economic welfare, then these *care and support interventions can increase the motivation of communities, commercial firms, and governments to provide additional care and support to affected populations.*

### 3. CARE AND SUPPORT ARE RIGHTS

The final and most important justification for the role of care and support is that they are fundamental human rights: *Providing HIV/AIDS care and support is an end in itself.*

Numerous international agreements and accords explain the responsibility of societies to ensure the well-being of all of their citizens, including people living with and affected by HIV/AIDS. Under these accords, societies are obligated to provide equal protections under the law and equal access to a broad range of services and benefits that are necessary for individual well-being. (Lazzarini 1998) These rights are summarized in Figure 3.

International law protects two major categories of human rights:

- # civil and political rights, which in general protect individuals from a loss of freedoms or from restraints on their liberties
- # economic, social, and cultural rights, which encompass fundamental entitlements, without which full and equal participation in society is difficult.

The right to health included in the Universal Declaration of Human Rights (UDHR, Article 25) incorporates important rights affected by HIV/AIDS. Among the civil and political rights affected by HIV/AIDS programs are the rights to autonomy, privacy, liberty, and the free exchange of information. Among the economic, social, and cultural rights affected are the rights to work, social security, education, full realization of human dignity and personality, improved health status for individuals and families, prevention of HIV infection, and provision of optimum care for individuals, and the right to development. (Lazzarini 1998)

Care and support programs respect and advance these human rights. They do so by strengthening individuals' so-called negative rights (the civil and political rights that must not be violated by governments) and their so-called positive rights (the economic, social, and cultural rights that must be actively promoted, protected, and supported).

**Figure 3.**  
**Selected Rights Enumerated in the**  
**Universal Declaration of Human Rights**  
**Adopted and proclaimed by the UN General Assembly, December 10, 1948**

Every individual has a right to:

- P** Life, liberty and security of person. (Article 3)
- P** Equal protection under the law without any discrimination. (Article 7)
- P** Freedom from arbitrary interference with privacy, family, home or correspondence, nor to attacks upon his honour and reputation. (Article 12)
- P** Freedom of movement and residence. (Article 13)
- P** Social security, and realization, within the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality. (Article 22)
- P** A standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. (Article 25)
- P** Motherhood and childhood are entitled to special care and assistance; All children, whether born in or out of wedlock, shall enjoy the same social protection. (Article 25)
- P** In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society. (Article 29)

#### 4. INTEGRATING HIV/AIDS PREVENTION, CARE, AND SUPPORT: "THE PREVENTION-AND-CARE CONTINUUM"

An important implication of the prevention-care dynamic is that effective responses to the HIV/AIDS pandemic will likely be characterized by approaches that integrate prevention, care, and support interventions. This integration concept is termed the "prevention-and-care continuum" and is discussed below.

Figure 4 presents a typology that forms a useful basis for discussing how communities, governments, and donors can integrate prevention, care, and support into their efforts to respond to HIV/AIDS. This typology describes three basic stages of an HIV/AIDS epidemic:

| Figure 4. The Typology of HIV/AIDS Epidemics |  |
|--|--|
| Stage of the Epidemic                        | Characteristics  |
| Nascent                                      | Prevalence is less than 5 percent in all known subpopulations presumed to practice high-risk behavior.   |
| Concentrated                                 | HIV prevalence has surpassed 5 percent in one or more subpopulations presumed to practice high-risk behavior, but prevalence among women attending urban antenatal clinics (proxies for the lower-risk "general" population) is still less than 5 percent. |
| Generalized                                  | HIV has spread far beyond the original subpopulations that practice high-risk behavior, which are now heavily infected; prevalence among women attending urban antenatal clinics is 5 percent or more.   |
| Source: World Bank (1997).                   |  |

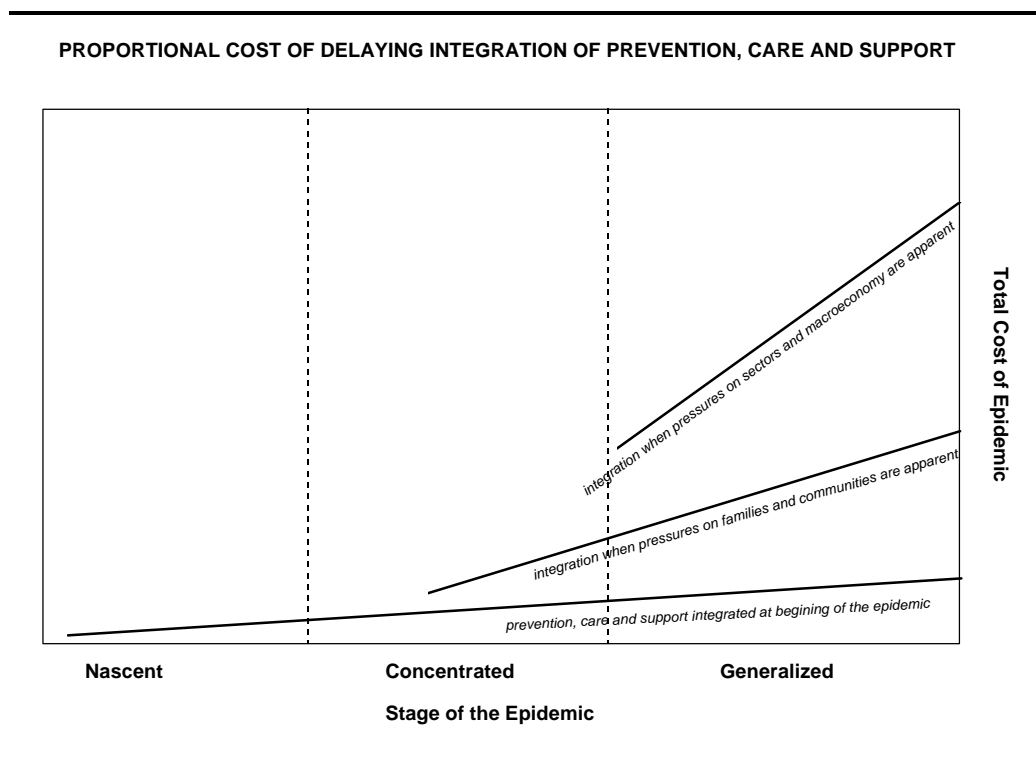
It is important to note that any typology can oversimplify the dynamics of infectious disease epidemiology. Within a single country, for example, there are often multiple epidemics at different stages. Also, progression from one stage to another is not inevitable: in some settings, the epidemic remains at the nascent stage for an extended period; in others, a concentrated epidemic never progresses to a generalized one.

The existence of a mutually reinforcing relationship between prevention and care implies that appropriate care and support interventions should be integrated with appropriate prevention interventions at the nascent, concentrated, and generalized stages of the HIV/AIDS epidemic. At each stage, therefore, communities, governments, and donors should ideally implement three types of strategies:

- # strategies to prevent transmission of HIV/AIDS, including management of sexually transmitted infections and behavior change interventions
- # strategies to provide care and support to people affected by HIV and AIDS, including home-based palliative and psychosocial care
- # strategies to buttress systems that are being or will be strained by the epidemic, such as enhancing the health system's ability to absorb AIDS patients or buttressing households' ability to generate income.

If care and support interventions enhance efforts to slow the transmission of HIV, as well as strengthening the ability of households, communities, and nations to cope with the negative effects of the epidemic, then it follows that governments and communities should invest both in care and support and in prevention from the outset. It also follows that the longer investments in care and support are delayed, the heavier the social, financial, and economic costs of the HIV/AIDS will be for the affected communities or countries. According to some observers (Lim 1993), the total costs of an epidemic can be expected to increase substantially when investments in care and support are delayed until the negative effects are apparent among families and communities and can be expected to increase further if such investments are delayed until the negative effects are apparent at the macroeconomic level, as shown in Figure 5.

For example, interventions to protect human rights are essential to more effective HIV prevention programs (Mann 1992). Started in the nascent stage of an epidemic, protection of human rights benefits PLWHAs and also enhances public health efforts to reach those persons who engage in high-risk behaviors such as commercial sex workers. Initial interventions that fail to consider the human rights of those in high-risk groups can undermine prevention efforts and potentially increase the spread of HIV (Moodie and Aboagye-Kwarteng 1993).



**Figure 5. The Proportional Cost of Delaying Integration of Prevention, Care, and Support**

Source: adapted from Cohen (1991), cited in Lim 1993.

The provision of voluntary counseling and testing at the concentrated stage of an epidemic can retard the rate of transmission of HIV from those most likely to be infected at the nascent stage (people who engage in highly unsafe behaviors or are placed in highly unsafe environments) to so-called bridge populations (those who have unprotected intercourse in high-risk situations and with regular partners who otherwise would not be at risk). This delay, in turn, makes it possible for resource managers to increase their expenditures on prevention, care, and support activities, and thereby to further retard the rate of infection. The results are cumulative and mutually supporting.

Likewise, early investments in establishing and improving systems for home-based care can prevent a disproportionate share of public sector health expenditures from being devoted to treatment of AIDS patients in hospitals. This frees resources to provide other types of acute care that require hospitalization.

In reality, most communities, governments, and donor are forced to prioritize their spending on prevention, care, and support interventions at each stage of the epidemic because of a general shortage of resources. Although there has been no comprehensive research on how to appropriately prioritize these types of interventions, there is a growing international consensus on some mixes of interventions that may be most appropriate at different stages of the epidemic in a given setting.

The Prevention-and-Care Continuum (Figure 6) illustrates how sets of interventions can integrate prevention, care, and support, even at the earliest stages of an epidemic, and illustrates the additional prevention-and-care interventions that become mandatory in response to the epidemic as it progresses from nascent to concentrated to generalized stages. The care and support interventions highlighted in the prevention-and-care continuum are illustrative and by no means comprehensive. More detailed and extensive information on the appropriate care and support interventions in the areas of human rights, palliative care, economic support, and psychosocial care can be found in the other discussion papers in this series.<sup>7</sup>

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<sup>7</sup>On human rights (Lazzarini 1998), palliative care (Sanei 1998), opportunistic infections (Kaplan et al. 1996/1998), psychosocial support (Schietinger 1998), community-based economic support (Donahue 1998), orphans (Hunter and Williamson 1998), and systems for delivering care and support (Schietinger and Sanei 1998).

# The HIV/AIDS Prevention & Care Continuum

## EXAMPLES

**Behavior change interventions (BCI) for Those Most Likely to Contact or Transmit (TMLCT) including condom social marketing and supportive messages for People Living with HIV/AIDS (PLWHA)**

**Programs and messages to combat HIV/AIDS stigma and discrimination**

**Programs to manage and control sexually transmitted infections (STIs)**

**Baseline risk behavior studies (e.g., sexual behavior, injecting drug use)**

**Voluntary HIV counseling and testing**

**Establish referral and support systems for people infected with HIV**

**Control and/or manage opportunistic infections**

**Improve tuberculosis (TB) management**

**Develop models for home-based care for people with HIV/AIDS**

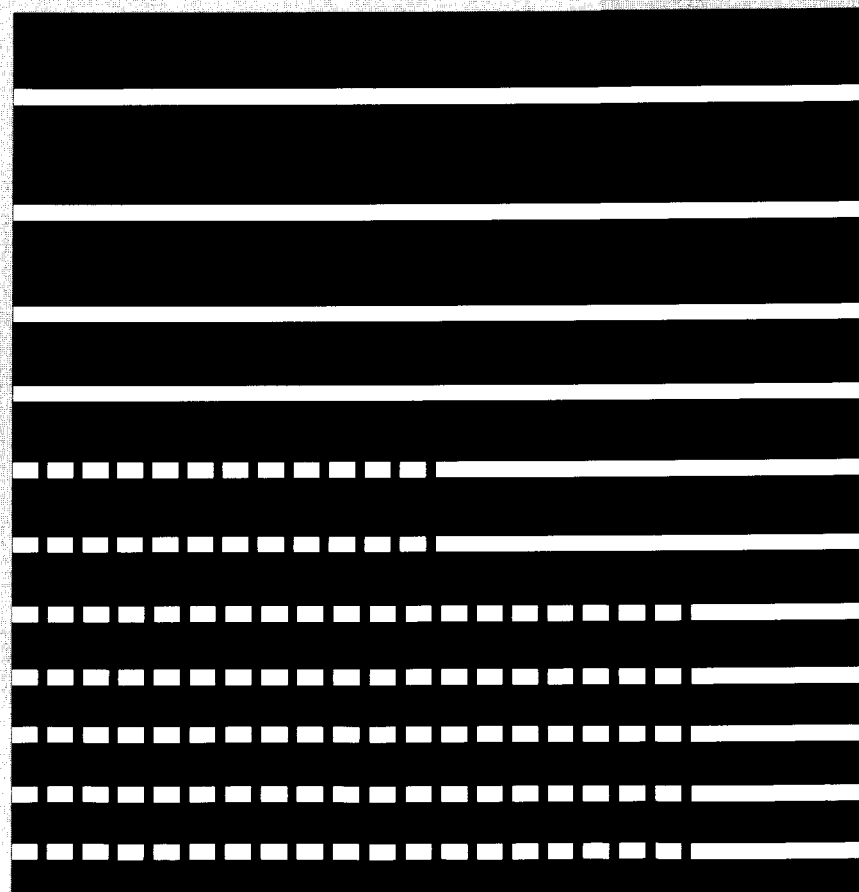
**Assist children who have lost parents to AIDS**

**Reinforce health systems to handle increased need for services**

## NASCENT

## CONCENTRATED

## GENERALIZED



These types of interventions are usually imperative no later than this stage of the epidemic.

These types of interventions may be appropriate at this stage of the epidemic.

Source: U.S. Agency for International Development, June, 1998.



## **5. CROSS-CUTTING PRINCIPLES FOR IMPLEMENTING CARE AND SUPPORT INTERVENTIONS**

A number of highly interrelated cross-cutting principles apply to HIV/AIDS prevention and care programming. These principles can be used as the criteria for deciding what programs to support and encourage and can be used to strengthen existing programs.

- # **Ensuring Community Ownership and Effective Participation:** In the face of limited donor and governmental resources, current and future programs to mitigate the effects of HIV/AIDS will be largely the result of community-level initiatives that utilize local resources. Communities must be assisted in developing the capacities they will need in the future by promoting their participating in the design, implementation, and evaluation of externally-funded HIV/AIDS care and support initiatives. The mode of participation should follow the principles of parity, inclusion, and representation.
- # **Planning for Sustainability:** The fact that the epidemic and its consequences will be with us for generations implies a need for sustainable responses that allow individuals, families, and communities to cope with HIV and AIDS. Care and support programs should strive to incorporate measures that will allow their benefits to be sustained within the combined technical capacity and resources of the host country and community. When appropriate, pilot projects should design care and support programs within a budget that is feasible when “scaled up” to a regional or national level rather than devoting resources to a more comprehensive program that could never be replicated when funding runs out.
- # **Building Local Capacity:** Programs should support national as well as community capacity rather than depending on external expertise for start-up and evaluation. Staff members of the programs should receive technical assistance, if necessary, to enable them to administer the program, apply evaluative information to make changes in programming, and provide consultation and technical assistance to other communities where the program will be established.
- # **Multi-Sectoral Collaboration:** With HIV/AIDS programs, collaboration among sectors ensures buy-in by important stakeholders, which is critical to a program’s success. The needs and issues related to HIV/AIDS care and support are diverse and cannot be met through the resources of a single sector.

For example, a care program within the health sector must be linked to resources and activities available through the education and welfare sectors to ensure that the needs of vulnerable children are met. Moreover, in most cases, multi-sectoral interaction enhances the prevention aspect of care-focused programs.

- # Decentralizing Programming: Resources for health care and health promotion need to be focused at the periphery of the health care system, and decisions about allocation of those resources must be made locally. In this way, government and donor resources can be leveraged to mobilize and sustain community-based responses.

## 6. CONCLUSIONS AND RECOMMENDATIONS

A number of conclusions become apparent from the discussions in this and its accompanying papers.

### 6.1 Conclusions

- # HIV/AIDS is a development problem: The impact of HIV/AIDS on individuals, families, communities, and nations are serious, and they undermine countries' ability to develop in a sustainable manner. These effects should be mitigated with appropriate care and support interventions.
- # Care and support enhance prevention efforts and prevention enhances care and support: There is clearly a mutually reinforcing relationship between HIV/AIDS prevention, care, and support efforts. A strong case can be made that care and support interventions, as a whole, seem to enhance the effectiveness of prevention efforts by strengthening the delivery of prevention services and by reducing the vulnerability of individuals and communities to infection. Increasingly effective prevention interventions, in turn, reduce the burdens associated with HIV infection and AIDS on families, communities, commercial firms, and governments, freeing up resources for the provision of care. This two-way effect sustains a cycle of benefits.
- # Care and support enhance human rights: Care and support interventions are appropriate mechanisms by which to assert and maintain individuals' rights to autonomy, health, and welfare.
- # Integrating prevention, care, and support is a multi-sectoral challenge: Care and support interventions are necessarily multi-sectoral, reflecting the multi-sectoral effects of the HIV/AIDS pandemic. Any credible, comprehensive approach to preventing and mitigating the effects of HIV/AIDS must fully engage individuals, communities, firms, governments, and international donors in appropriately integrating prevention, care, and support activities.
- # The relationships between prevention, care, and support are under-researched: No comprehensive research has yet been published on the prevention-care dynamic. We do not know the strength of the effect of care and support provision on the performance of prevention efforts in different settings. Nor do we know the strength of the effect of reduced HIV transmission on expanding the provision of care and support. While the relationships between prevention,

care, and support are intuitive and are buttressed by some grey literature, decision-makers need more specific and generalizable research results to guide them in integrating prevention, care, and support in community, national, and international responses to the pandemic.

### **6.2 Programmatic Recommendations**

The following is a set of recommendations for the integration of prevention, care, and support in national and international responses to the HIV/AIDS pandemic. These recommendations are synthesized from the individual discussion papers in this series and are based on the experiences and lessons learned of individuals and organizations at the forefront of the debate on HIV/AIDS care and support.

#### **Human Rights**

- # Integrate human rights standards into both the planning and implementation of AIDS programs. (See suggested framework for impact assessment in the paper on Human Rights and HIV/AIDS by Zita Lazzarini, 1998).
- # Conduct a national human rights assessment using the UNAIDS Guidelines

#### **Palliative Care**

- # Assist countries to develop national clinical management guidelines for HIV.
- # Assist countries to develop national pain management guidelines and incorporate appropriate drugs on the country's essential drug list.
- # Improve systems to prophylaxe common opportunistic infections (including Tuberculosis)
- # Provide enhanced STD treatment for People Living with HIV and AIDS

#### **Psychosocial Care**

- # Establish strong links between voluntary counseling and testing services and health services.
- # Incorporate peer support into prevention and care programs to provide PLWHAs with mutual support for "living positively with AIDS"

### **Socioeconomic Care**

- # Strengthen community safety nets by stimulating community planning processes to galvanize community responses to the epidemic.
- # Support the implementation of microcredit schemes in communities heavily impacted by HIV/AIDS.

### **Care of Orphans**

- # Support programs that strengthen the family capacity to cope. In addition, protect women's and children's property rights.
- # Stimulate and strengthen community-based responses.
- # Ensure that governments protect the most vulnerable children. Specifically, intervene to protect abused or neglected children; build adoption and foster care mechanisms; and protect working children.
- # Build the capacity of children to support themselves. Specifically: change community standards and school fees to enable children to stay in school; reduce labor demands on households by providing labor-saving mechanisms for the community, such as piped in water; and protect children from exploitation by strengthening laws and funding and training child welfare workers.

### **Systems for Delivering Care**

- # Provide technical assistance and capacity building in "scaling up" community-based programs.
- # Provide technical assistance and capacity building in strengthening the peripheral levels of the primary health care system.
- # Provide technical assistance and capacity building in rational pharmaceutical management to assure availability of appropriate drugs for pain and symptom management and prophylaxis and treatment of opportunistic infections.

### 6.3 Proposed Research Agenda

Despite the experience and knowledge gained thus far in implementing prevention and care interventions, we do not know enough about the efficacy of many innovative care and support programs in mitigating the effects of the HIV/AIDS pandemic on individuals, families, communities, health systems, productive sectors, and the general political and societal stability of nations. Little, too, is known about the exact nature of the relationship between care and support activities and the strength of the dynamic by which they enhance prevention activities. Less is known about the exact costs of delivery of care and support services.

There is strong experiential evidence of the mutually enhancing relationship between care, support, and prevention, gained from HIV/AIDS programs conducted worldwide over the past decade. Nonetheless, it is difficult for countries to strategically and appropriately select the mix of prevention, care, and support interventions without information on the cost-effectiveness and cost-benefit characteristics of individual interventions. Determining efficacy and cost, therefore, should be a priority for the international community over the next few years.

Specific research recommendations from the accompanying discussion papers are summarized below.

#### **General Research on the Prevention-Care Dynamic**

- # What are the factors that influence the total financial, economic, health and social costs of delaying appropriate integration of prevention, care and support?
- # To what extent is the prevention-care dynamic self-generating or self-sustaining?
- # What care and support interventions are priorities at the nascent, concentrated, and generalized stages of an epidemic?
- # What care and support interventions have the greatest prevention benefits, among which populations, and under what circumstances?

### **Human Rights**

- # Track the relationship between burdens on human rights and vulnerability to HIV with the aim of determining how interventions could reduce burdens, and thus vulnerability.
- # Examine the relationship between the promotion of human rights, reducing HIV transmission, and increasing the well-being of those with HIV.
- # Conduct research on equity of access and resource allocation.

### **Palliative Care**

- # Evaluate the impact of community-based TB prophylaxis for co-infected people with HIV on overall incidence and morbidity of TB.
- # Evaluate the impact of providing prophylaxis for opportunistic infections for people living with HIV/AIDS.
- # Conduct operational research to examine the efficacy of home-based care interventions for reducing the cost of health care.
- # Examine the relationship between provision of palliative care, including pain management, at the community level, and health care utilization.

### **Psychosocial Care**

- # Evaluate the differential effect of including follow-on care and support services linked to voluntary testing and counseling on enhancing the effect of VCT programs and on the quality of life of their beneficiaries
- # Evaluate the efficacy of peer support interventions in promoting successful coping strategies and HIV prevention.

### **Socioeconomic Care**

- # Evaluate the cost-effectiveness and impact of providing microcredit in communities with high HIV/AIDS prevalence.
- # Compare interventions to enhance community safety nets in terms of cost-effectiveness, sustainability, and impact on affected families.

### **Care of Orphans**

- # Evaluate the well-being of children maintained in the community through orphan assistance programs.
- # Evaluate the cost-effectiveness of community assistance programs in terms of outputs such as levels productivity, level of education in the community, and HIV sero-prevalence.

### **Systems for Delivering Care**

- # Evaluate the cost-effectiveness and impact of providing rational pharmaceutical management and health care delivery at the peripheral level of the health system.
- # Compare centralized and decentralized health care in terms of scope of coverage (number of individuals reached) and cost-effectiveness.





## Annex A: References

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- Armstrong, Jill, and Eduard Bos. 1992. "The Demographic, Economic and Social impact of AIDS," in J. Mann and D. Tarantola, eds., *AIDS in the World*. Cambridge, MA.: Harvard University Press.
- Barnett, Tony, and Piers Blaikie. 1990. *Community Coping Mechanisms in the Face of Exceptional Demographic Change*. Final Report to the Overseas Development Administration. London: ODA (July).
- Broomberg, J., and D. Schopper. 1996. "The Cost of HIV Prevention," in J. Mann and D. Tarantola, eds. *AIDS in the World II*. New York: Oxford University Press.
- Buve, S., D. Foster, C. Mbwili, E. Mungo, N. Tollenare, and M. Zeko. 1994. "Mortality among Female Nurses in the Face of the AIDS Epidemic: A Pilot Study in Zambia," *AIDS* 8(3):396.
- Cohen, D. 1991. "The Economic Impact of AIDS," unpublished. Cited in David Lim, "The Economic Impact of AIDS in Malaysia," in David Bloom and Joyce Lyons, eds., *The Economic Impact of AIDS in Asia*, 1993.
- Cohen, M. S., I. F. Hoffman, R. A. Royce, P. Kazembe, J. R. Dyer, C. C. Daly, D. Zimba, P. L. Vernazza, M. Maida, S. A. Fiscus, J. J. Econ. 1997. "Reduction of Concentration of HIV-1 in Semen after Treatment of Urethritis: Implications for Prevention of Sexual Transmission of HIV-1," *Lancet* 349:1868-73.
- Corbett, Jane. 1988. "Famine and Household Coping Strategies," *World Development* 16 (9):1099-112.
- CSIS. 1994. *Global HIV/AIDS: A Strategy for U.S. Leadership*. Consensus Report of the Center for Strategic and International Studies (CSIS) Working Group on HIV/AIDS, 1994.
- Donahue, Jill. 1998. *Community-Based Economic Support for Households Affected by HIV/AIDS*, Discussion Paper on HIV/AIDS Care and Support No. 6. Arlington, VA: Health Technical Services (HTS) Project for USAID (June).

Fortsyth, Steve., Julia Hasbun and Marthe Butler de Lister *AIDS and its Potential Economic Impact on Free Trade Zones in Santo Domingo, the Dominican Republic*. The AIDSCAP Electronic Library CD-ROM. Arlington, VA: AIDS Control and Prevention (AIDSCAP) Project, Family Health International, for USAID.

Godwin, Peter. 1997. *Socio-Economic Implications of the Epidemic*. New Delhi: UNDP Regional Project on HIV and Development.

Hamilton, Kim. 1994. "The HIV and AIDS Pandemic as a Foreign Policy Concern," *The Washington Quarterly* 17(1):201–15.

Hunter, Susan, and John Williamson. 1998a. *Children on the Brink: Strategies to Support Children Isolated by HIV/AIDS*. Arlington, VA: Health Technical Services (HTS) Project for USAID (January).

———. 1998b. *Responding to the Needs of Children Orphaned by HIV/AIDS*. Discussion Paper on HIV/AIDS Care and Support No. 7. Arlington, VA: Health Technical Services (HTS) Project for USAID (June).

Kaplan, J. E., D. J. Hu, K. Holmes, H. W. Jaffe, H. Masur, and K. M. DeCock. 1996/1998. "Preventing Opportunistic Infections in Human Immunodeficiency Virus–Infected Persons: Implications for the Developing World," *American Journal of Tropical Medicine and Hygiene* 55(1). Reprinted with permission as Discussion Paper on HIV/AIDS Care No. 4. Arlington, VA: Health Technical Services (HTS) Project (June).

Lazzarini, Zita. 1998. *Human Rights and HIV/AIDS*, Discussion Paper on HIV/AIDS Care and Support No. 2. Arlington, VA: Health Technical Services (HTS) Project for USAID (June).

Lim, David. 1993. "The Economic Impact of AIDS in Malaysia," in David Bloom and Joyce Lyons, eds., *The Economic Impact of AIDS in Asia*, 1993.

MacNeil, J. . 1996. *Mitigating the Impact of HIV Through Care and Social Support*, The AIDSCAP Electronic Library CD-ROM. Arlington, VA: AIDS Control and Prevention (AIDSCAP) Project, Family Health International, for USAID.

Maher, D., H. P. Hausler, M. C. Raviglione, N. Kaleeba, T. Aisu, B. Fourie, and P. Nunn. 1997. "Tuberculosis Care in Community Care Organizations in Sub-

- Saharan Africa: Practice and Potential,” *International Journal of Tuberculosis and Lung Disease* 1(3):276–83.
- Mann, J. 1992. “AIDS — The Second Decade: A Global Perspective,” *The Journal of Infectious Diseases* 165(2):245–50.
- Mann, Jonathan, and Daniel Tarantola. 1992. *AIDS in the World*. Cambridge, MA: Harvard University Press.
- . 1996. *AIDS in the World II*. New York: Oxford University Press.
- Martin, A. L. 1996. “The Cost of HIV/AIDS Care,” in J. Mann and D. Tarantola, eds. *AIDS in the World II*. New York: Oxford University Press.
- Moodie, R., T. Aboagye-Kwarteng. 1993. “Editorial Review: Confronting the HIV Epidemic in Asia and Pacific: Developing Successful Strategies to Minimize the Spread of HIV Infection,” *AIDS* 7(12):1543–51.
- National Research Council. 1996. *Preventing and Mitigating AIDS in Sub-Saharan Africa*. Washington D.C.: National Academy Press
- Panos Institute. 1992. “Rural Households and Food Security,” in *The Hidden Cost of AIDS*. London: The Panos Institute, 1992.
- Raviglione, M. C., A. D. Harries, R. Msiska, D. Wilkinson, and P. Nunn. 1997. “Tuberculosis and HIV: Current Status in Africa,” *AIDS* 11 (Suppl B): S115–23.
- Raviglione, M., P. P. Nunn, A. Kichi, R. J. O’Brien. 1996. “The Pandemic of HIV–Associated Tuberculosis,” in J. Mann and D. Tarantola, eds., *AIDS in the World II*. New York: Oxford University Press.
- Sanei, Linda. 1998. *Palliative Care for HIV/AIDS in Less Developed Countries*. Discussion Paper on HIV/AIDS Care and Support No. 3. Arlington, VA: Health Technical Services (HTS) Project for USAID (June).
- Schietinger, Helen. 1998. *Psychosocial Support for People Living with HIV/AIDS*, Discussion Paper on HIV/AIDS Care No. 5. Arlington, VA: Health Technical Services (HTS) Project for USAID (June).
- Schietinger, Helen, and Linda Sanai. 1998. *Systems for Delivering HIV/AIDS Care*. Discussion Paper on HIV/AIDS Care No. 8. Arlington, VA: Health Technical Services (HTS) Project for USAID (June).

- Tibaijuka, Anna Kabumulo. 1997. "AIDS and Economic Welfare in Peasant Agriculture: Case Studies from Kagabiro Village, Kagera Region, Tanzania," *World Development* 25(6).
- UNAIDS. 1997. "Children Living in a World with AIDS: Facts and Figures," 1997 *World AIDS Campaign*. Geneva: Joint United Nations Programme on HIV/AIDS. (Available at [www.unaids.org/events/wad/1997/facts.html](http://www.unaids.org/events/wad/1997/facts.html).)
- UNDP. 1994. *The Socio-Economic Impact of HIV on Agriculture: An Issues Paper*. New York: United Nations Development Programme, Global Office, AIDS Program.
- USAID. 1996. *USAID Responds to HIV/AIDS: Report on the Fiscal Years 1995 and 1996 HIV/AIDS Prevention Programs of the United States Agency for International Development*. Washington, DC: U.S. Agency for International Development.
- U.S. Bureau of the Census. 1996. *World Population Profile 1996, with a Special Chapter Focusing on Adolescent Fertility in the Developing World*. Washington, DC: Government Printing Office.
- . 1997. *Recent HIV Seroprevalence Levels by Country: January 1997*, Research Note 23. Washington, DC: U.S. Bureau of the Census, Health Studies Branch, International Programs Center, Population Division.
- U.S. Department of State. 1992. *The Global AIDS Disaster: Implications for the 1990s*. Washington, DC: U.S. Department of State, Office of the Secretary of State.
- Whiteside, Alan, and John Stover. 1997. "The Demographic and Economic Impact of AIDS in Africa," *AIDS* 11(Suppl B):555–61.
- WHO. 1991. *Review of Six HIV/AIDS Home Care Programs in Uganda*. Geneva: World Health Organization.
- World Bank. 1997. *Confronting AIDS: Public Priorities in a Global Epidemic*. Policy Research Report. Washington, DC: World Bank.

## Annex B: Acronyms

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Below is a list of the acronyms used in this report.

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| CSIS    | Center for Strategic and International Studies   |
| FTZ     | Free trade zone  |
| GDP     | Gross domestic product   |
| GPA     | Global Programme on AIDS (WHO)   |
| HDI     | Human Development Index  |
| HTS     | Health Technical Services Project  |
| NGO     | Nongovernmental organization   |
| OI      | Opportunistic infection  |
| PLWHA   | Person/people living with HIV/AIDS   |
| STI     | Sexually transmitted infection   |
| TASO    | The AIDS Support Organization (Uganda)   |
| TB      | Tuberculosis   |
| UDHR    | Universal Declaration of Human Rights  |
| UN      | United Nations   |
| UNAIDS  | Joint United Nations Programme on HIV/AIDS   |
| UNDP    | United Nations Development Programme   |
| USAID   | United States Agency for International Development   |
| WHO     | World Health Organization  |
| WHO/GPA | World Health Organization's Global Programme on AIDS<br>(replaced on January 1, 1996, by UNAIDS) |